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DOI:

[10.1136/archdischild-2018-316595](https://doi.org/10.1136/archdischild-2018-316595)

*Document Version*

Peer reviewed version

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*Citation for published version (APA):*

Bennett, S., Heyman, I., Coughtrey, A., Buszewicz, M., Byford, S., Dore, C., Fonagy, P., Ford, T., Moss-Morris, R., Stephenson, T., Varadkar, S., Walker, E. A., & Shafran, R. (2019). Assessing feasibility of routine identification tools for mental health disorder in neurology clinics. *Archives of Disease in Childhood*, 104(12), 1161-1166. <https://doi.org/10.1136/archdischild-2018-316595>

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**Assessing feasibility of routine identification tools for mental health disorder in  
neurology clinics**

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## **ABSTRACT**

### **Objective**

We aimed to test the feasibility of using an online parent-completed diagnostic assessment for detecting common mental health disorders in children attending neurology clinics. The assessment does not require intervention by a mental health professional or additional time in the clinic appointment.

### **Setting**

Two parallel and related screening studies were undertaken:

Study 1: Tertiary paediatric neurology clinics

Study 2: Secondary and tertiary paediatric neurology clinics

### **Patients**

Study 1: 406 Young people aged 7-18 attending paediatric neurology clinics

Study 2: 225 Young people aged 3-18 attending paediatric epilepsy clinics

### **Interventions**

Parents completed online versions of the Strengths and Difficulties Questionnaire (SDQ) and Development and Wellbeing Assessment (DAWBA).

### **Main outcome measures**

We investigated: the willingness of families to complete the measures, proportion identified as having mental health disorders, time taken to complete the measures and acceptability to families and clinicians.

### **Results**

The mean total difficulties score of those that had completed the SDQ fell in the 'high' and 'very high' ranges. 60% and 70% of the DAWBAS completed met criteria for at least one DSM-IV disorder in study 1 and 2 respectively. 98% of the parents reported that the screening methods used were acceptable.

**Conclusions:** Use of an online, automated screening process is a feasible method of detecting mental health disorders in children with chronic illnesses whilst minimising burden on families and clinicians. The process was highly acceptable to families who completed the full screening process and could provide a viable option of integrating mental health assessment into routine paediatric care.

Common childhood mental health disorders are up to five times more frequent in children with neurological conditions than in those without a chronic illness, yet ‘contemporary standards of practice fail to integrate screening and treatment of the comorbidities into routine clinical care’[1] and there is a high unmet need for treatment [2]. This situation is not unique to neurological conditions; up to 80% of those with a chronic illness and symptoms of a mental health disorder are not in contact with child and adolescent mental health services [2-6]. Left untreated, mental health disorders seriously impact social, occupational and educational functioning into adulthood [7-8].

Whilst most paediatricians may consider it a part of their responsibilities to identify mental health difficulties [9] there are a number of barriers to accurate and timely identification. One study found that US paediatricians correctly identified only 25% of children meeting criteria for impairing symptoms of emotional/behavioural disorder as having definite or severe mental health difficulties [10] and a UK study found that General Practitioners have difficulty identifying mental health needs in children [11]. Physical health specialists may also not have the time to ask about and/or assess mental health; mental health discussions can take up a significant proportion of clinic time [12-13] and clinicians may not wish to ‘uncover a can of worms’ that will warrant a significant amount of extra work.

One solution to the challenges in identifying mental health disorders is to embed mental health specialists within paediatric teams [14-15]. However, many paediatric centres do not have access to embedded psychiatric liaison services, despite guidance to the contrary [16] and provision is variable where such services do exist [17]. Given the already stretched capacity of child and adolescent mental health services, it may be unfeasible for a qualified mental health professional to be co-located within all paediatric clinics with the sole purpose of identifying and treating mental health difficulties.

One potential, pragmatic solution is a routine computerised screening programme,

which would not need the expertise of a mental health professional to administer and would not take up time within the neurology clinic appointment. The present paper reports on two related studies investigating the feasibility of such an automated screening programme (the Development and Wellbeing Assessment (DAWBA));[18], delivered at the point of care in paediatric clinics.

The psychometric properties of the DAWBA within paediatric clinics, particularly in epilepsy clinics are well established [19-20], therefore the purpose of this research was to determine the *feasibility* of this method as a means to identify children and young people who would benefit from further assessment or intervention for mental health difficulties in neurology services. In line with NIHR guidance on feasibility studies [21], the specific objectives were to determine the:

- Numbers of families who consent to screening;
- Numbers of families who complete screening measures;
- Proportion with a mental health disorder;
- Overall acceptability to families and clinicians.

The first study established initial feasibility in a neurology service within a specialist paediatric hospital. The second study built on this by offering the screening programme within both the specialist hospital and several paediatric epilepsy clinics in general hospitals.

## **METHODS**

### **Materials**

**Strengths and Difficulties Questionnaire (SDQ)[22].** This is a commonly used and psychometrically robust measure to identify mental health difficulties, including both emotional and behavioural difficulties. It consists of 25 items, divided into 5 scales (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems), in addition to an impact supplement which asks the respondent whether they think

the young person has a problem with emotions or behaviour, and if so asks about chronicity, distress, social impairment and burden to others. Scores on each subscale and the impact scale can be categorised into four ranges: close to average, slightly high, high, and very high. It can be completed by the parent if the child is less than 11 years of age, or by the parent and young person if they are age 11 or older. Only the parent-report version was used in this study. The SDQ has been validated across the wide age-range of children and young people seen within neurology clinics (3-18)[23], and used in those with Autism Spectrum Disorder [24] and Intellectual Disabilities [25], known to be highly prevalent in young people with neurological conditions [26].

**Development and Wellbeing Assessment (DAWBA)[27].** The SDQ is part of the longer Development and Wellbeing Assessment (DAWBA), a package of interviews, questionnaires and rating techniques designed to generate ICD-10 and DSM-IV or DSM-5 psychiatric diagnoses on 5-17 year olds [27]. The DAWBA takes 30-50 minutes to complete in a community sample. It is used widely in child and adolescent mental health services internationally and has been demonstrated to be acceptable to families attending child and adolescent mental health services [28]. There are a variety of formats including computer-administered interviews that are available via the internet in a number of languages. The online DAWBA automatically generates probabilities that the child or young person meets diagnostic criteria. It can be ‘hand’ rated by a trained clinician, who can override the computer diagnosis should they consider subclinical symptoms to be of sufficient severity, or should they consider areas where an informant’s information may be inaccurate or they have misunderstood the question. In both studies, the DAWBA was completed by parents and rated by a qualified clinical psychologist who was trained in DAWBA rating.

**Reports** Once completed, the SDQ and DAWBA can provide automatically generated reports. One report is ‘parent-friendly’ explaining the results in non-expert terms, and the

other is for professionals. Parents are informed that they can print off the professionals' report and can take this to their GP or other appointments, to help them get the support needed. The report site also directs parents and young people to appropriate self-help resources.

**Acceptability.** Participants were asked to rate how acceptable they found taking part in the study on a five point Likert scale from 1 = not at all to 5 = completely.

## **Process**

Both studies implemented a routine voluntary screening programme within neurology clinics. The consent process differed in studies due to ethical requirements. In Study 1 research assistants approached families within clinic. In study 2, clinic staff informed patients about the research and research assistants were required to wait for families to approach them. Figure 1 illustrates the screening process used for both studies. In both studies, a computer-generated algorithm identified participants who were above a significant symptom threshold on the SDQ; only participants who scored above this threshold went on to the complete the DAWBA.

Study 1 was conducted primarily in epilepsy clinics in a specialist children's hospital; other paediatric neurology clinics sampled included those for cerebrovascular conditions and migraine. The sample was children aged 7-18 years attending a tertiary referral neurology clinic for assessment or treatment in a specialist paediatric hospital. Exclusion criteria were minimal and restricted to those with profound intellectual disability. Although the SDQ has been translated into several languages, parents who did not understand English sufficiently well to be able to access the screening measures were excluded, due to lack of funding for translators to discuss the results with families. Full informed consent was taken prior to SDQ completion.

Study 1 was associated with a simultaneous intervention study in which children and young people meeting criteria for impairing symptoms of mental health disorder were offered



brief psychological intervention. The results of this study are reported elsewhere [29].

Study 2 expanded on study 1 to include general hospitals and a wider age range of young people. Study 2 was multisite, including epilepsy clinics in general hospitals in addition to the specialist paediatric hospital. Only epilepsy clinics were included. Many interested families were unable to participate in study 1, as their child was under 7 years old. The age criterion was therefore expanded to children and young people aged 3-18 years attending epilepsy clinics at any of the participating recruitment sites. As in study 1, exclusion criteria were minimal and restricted to those with profound intellectual disability or those who did not understand English sufficiently well to access the measures. Full informed consent was taken only once a participant had scored above the threshold for impairing symptoms on the SDQ.

Study 2 formed part of an NIHR Programme Development Grant (RP-PG-0616-10007) investigating the feasibility and acceptability of study recruitment and measures in a more diverse range of clinics and to gather data on usual treatment of mental health difficulties in the children attending these clinics. The study aimed to recruit 46 participants for DAWBA completion and description of usual treatment. Data on usual treatment are reported elsewhere [30]. These 46 participants were invited to complete a bespoke questionnaire on acceptability of the study process.

## **Ethics**

Both studies received full ethical approval from Camden and Islington Research Ethics Committee (Study 1) and the South East Coast – Surrey Research Ethics Committee (Study 2).

## **RESULTS**

## Study 1

Four hundred and nineteen parents consented to take part in the screening study, of whom 285 (68%) had epilepsy and 134 (32%) had other neurological conditions, including neurovascular conditions, movement disorders and migraine. Figure 2 shows the flow chart of study participation. The age and gender distribution was similar at all stages of screening suggesting that those completing the DAWBA were representative of the initial sample (Table 1).

TABLE 1. Demographics of Study 1 and Study 2 participants

Stage	Study 1		Study 2	
	Mean Age (Years) SD	Male (%)	Mean Age (Years) SD	Male (%)
SDQ completion	11.51 (3.12)	50	10.29 (5.53)	53
SDQ above threshold	11.83 (3.13)	50	10.39 (6.24)	66
DAWBA Completion	11.3 (3.93)	55	9.68 (3.87)	19

The mean total difficulties score of the sample completing the SDQ was 16.9 (SD=8.19) and impact score was 4.05 (SD = 3.42). These fall within the ‘high’ and ‘very high’ ranges respectively. Of the 124 DAWBAs completed, 87 (70% of DAWBAs completed and 20.8% of the full sample) of these met full criteria for at least one DSM-IV disorder and a further 8 categorised by the DAWBA as possibly meeting criteria (Table 2). Forty-four participants met or possibly met criteria for one disorder and 51 met or possibly met criteria for two or more disorders. The mean number of diagnoses was 1.83 (SD = 1.55).

TABLE 2: Number of DAWBAs meeting diagnostic threshold for DSM-IV (Study 1) or DSM-5(Study 2) DAWBAs

Disorder	Study 1			Study 2			Total		
	Meets criteria (%)	Unsure (%)	Does not meet criteria (%)	Meets criteria (%)	Unsure (%)	Does not meet criteria (%)	Meets criteria (%)	Unsure (%)	Does not meet criteria (%)
Any	70.2	6.5	23.4	63.0	6.5	30.4	68.2	6.5	25.3
Separation Anxiety	13.7	1.6	84.7	17.4	2.2	80.4	14.7	1.8	83.5
Specific Phobia	10.5	1.6	87.9	0	0	100.0	7.6	1.2	91.2
Social Phobia	4.0	0.8	95.2	0	0	100.0	2.9	0.6	96.5
Panic Disorder	0	0	100.0	0	2.2	97.8	0	0.6	99.4
Agoraphobia	0	0	100.0	0	0	100.0	0	0	100.0
PTSD	0.8	0	99.2	0	0	100.0	0.6	0	99.4
OCD	0	0.8	99.2	0	0	100.0	0	0.6	99.4
BDD	0	0	100.0	0	0	100.0	0	0	100.0
GAD	8.9	0.8	90.3	6.5	0	93.5	8.2	0.6	91.2
Other Anxiety	0.8	0	99.2	0	0	100.0	0.6	0	99.4
DMDD	0.8	0	99.2	0	0	100.0	0.6	0	99.4
Major Depression	11.3	1.6	87.1	6.5	0	93.5	10	1.2	88.8
Other Depression	0	0	100.0	0	0	100.0	0	0	100.0
Undiff Anx/dep	0	0	100.0	0	0	100.0	0	0	100.0
Mania/bipolar	0	0	100.0	0	0	100.0	0	0	100.0
Social	0	0	100.0	0	0	100.0	0	0	100.0
Selective Mutism	0	0	100.0	0	0	100.0	0	0	100.0
Attachment Disorder	0	0	100.0	0	0	100.0	0	0	100.0
ADHD Combined	14.5	5.6	79.8	10.9	0	89.1	13.5	4.1	82.4
ADHD Inattentive	0	0.8	99.2	4.3	0	95.7	1.2	0.6	98.2

ADHD Hyp-Imp	0.8	0	99.2	0	0	100.0	0.6	0	99.4
Other	0	0	100.0	0	0	100.0	0	0	100.0
Hyperactivity	0	0	100.0	0	0	100.0	0	0	100.0
ODD	29.8	1.6	68.5	30.4	2.2	67.4	30	1.8	68.2
Conduct Disorder	0	0	100.0	0	0	100.0	0	0	100.0
Other Disruptive	0	0	100.0	0	0	100.0	0	0	100.0
PDD/Autism	20.2	10.5	69.4	26.1	4.3	69.6	21.8	8.8	69.4
Tic Disorder	0.8	0.8	98.4	0	0	100.0	0.6	0.6	98.8
Eating Disorder	0	0	100.0	0	0	100.0	0	0	100.0
Psychosis	0	0	100.0	0	0	100.0	0	0	100.0
Stereotypic	0	0	100.0	0	0	100.0	0	0	100.0
Any other	0	0	100.0	0	0	100.0	0	0	100.0

Abbreviations:

ADHD = Attention Deficit Hyperactivity Disorder; BDD = Body Dysmorphic Disorder; DMDD = Disruptive Mood Regulation Disorder; GAD = Generalised Anxiety Disorder; OCD = Obsessive Compulsive Disorder; ODD = Oppositional Defiant Disorder; PDD = Pervasive Developmental Disorder; PTSD = Post Traumatic Stress Disorder

## **Study 2**

Of those attending clinic, 233 parents agreed to take part in the initial screening.

Figure 3 shows the flow chart of study participation. The mean total difficulties score of the sample was 16.39 (SD = 7.52), indicating a score on the borderline of the high and very high range, and impact score was 3.7 (SD = 3.37), which falls in the very high range.

Of the 46 completed DAWBAs, 29 (61.7% of completed DAWBAs) met full criteria for a DSM-5 Disorder, and a further three possibly met diagnostic criteria (Table 2). Eight (17.02% of DAWBAs completed) of these met criteria for two DSM-5 disorders.

### **Service use and unmet need**

The 46 parents who completed the DAWBA in Study 2 were asked about their child's use of mental health services to date. 16/46 reported that they had experience of previous or current support for their child's difficulties and 10 of these considered it useful.

### **Acceptability**

Of the 46 parents who completed a questionnaire on acceptability, 45 (98%) reported that the methods were acceptable.

Clinicians reported that it did not interfere with clinic processes. Some clinicians said that it reduced the length of clinic appointments as patients felt that their mental health needs were being considered and therefore did not need to raise them in detail within the neurology appointment itself.

## **DISCUSSION**

The pragmatic feasibility studies reported here indicate that it is practical and acceptable to use the online SDQ with automatic progression to the DAWBA for identifying children and young people with chronic neurological conditions who may benefit from further assessment

and/or treatment of mental health difficulties. The SDQ findings reveal highly elevated rates of mental health difficulties (57% and 54%). This rate is similar to other studies investigating screening instrument use in paediatric epilepsy; for example, Wagner and colleagues (2016) found that 50% of young people attending a US paediatric epilepsy clinic screened positive for mental health difficulties [31]. The associated intervention and usual treatment studies described elsewhere [29, 30] demonstrated that a large proportion of those identified as having mental health needs had never received mental health support. Of those completing DAWBAs, 20% of the children in Study 1 were in current receipt of mental health treatment and 35% of children in Study 2 had either past or current support for the mental health difficulties.

The lack of child mental health provision in paediatric settings, and the subsequent impact on missed diagnoses has been revealed in national surveys [32], and led to the UK Commissioning for Quality and Innovation (CQUINs) payments framework incentivising the use of the SDQ to screen for mental health problems in children and young people with chronic illnesses, including those with neurological conditions [33]. The present study suggests that use of the online SDQ in clinic waiting rooms with automatic transfer to the DAWBA may be a pragmatic way of ensuring that such screening can be implemented successfully with minimal need for support or time from clinicians. The automatic computer system also ensured access to more detailed assessment where necessary, whilst minimising burden for families, particularly in those in whom no difficulties were identified.

Whilst it is debatable whether dichotomising presence or absence of diagnosis is helpful for defining clinical thresholds for services, the SDQ alone gives limited information regarding the types of difficulties experienced by a child/young person. According to Asato [34], ‘one important potential barrier to screening is the clinician’s concern that they might

not know what steps to take next after obtaining a positive screen' (p. 100). Online diagnostic interviews, such as the DAWBA may help bridge this gap. For example, in the UK, national guidelines based on diagnosis (NICE Guidelines), direct clinicians and patients to the correct interventions for conditions such as attention deficit hyperactivity disorder (ADHD), anxiety disorders and depression.

In addition to providing clinicians with clear next steps for treatment, the DAWBA may empower patients to advocate for the evidence-based treatments that their child needs. As reported in previous studies, large numbers of the participants with identified mental health needs did not have adequate support [2-5]. Whilst some have cautioned against the use of screening where adequate support is not available for onward referral [35], one advantage of the DAWBA is the automatically generated DAWBA report which clearly sets out the identified symptoms and the probable diagnoses. This may be used by these families to empower them to seek further professional advice, request referrals to services, and/or to take the report to appointments with health professionals to assist with assessment and diagnosis. The report can also be formatted to select, and direct families to, appropriate self-help resources, which are now recommended by UK NICE guidance as a first-line treatment option for several common mental health disorders. Further research is needed to investigate the extent to which the identification process facilitates access to further assessment and intervention.

The main weakness of these feasibility studies is the lack of information regarding acceptability of the procedure to those who chose not to complete the screening process, however they were representative of those approached in terms of age and gender. Research has demonstrated that people from lower SES are the most likely to have co-occurring mental and physical health conditions [36] but reduced access to care. It is possible that this group may be less able to access online screening methods. The lack of information regarding

socioeconomic status of participants is a limitation of this study and future work should ensure such information is collected.

Further research is needed to explore such barriers to completion of the screening instruments. The DAWBA can be a long assessment, particularly if children demonstrate difficulties across a range of areas, as is common in children with neurological conditions [26] and borne out within the present studies. Last and colleagues [28] asked parents to complete a questionnaire about their experiences of the DAWBA. Specifically, parents were asked to rate how easy the assessment was to complete and whether they could have completed it independently over the internet. Open-ended questions asked whether the DAWBA included any topics that they thought should be omitted, whether it missed out any topics that should be included and whether anything would have made completing the DAWBA easier. Finally parents were asked if the DAWBA changed the way that they thought about their child's difficulties. Whilst most parents found it to be acceptable, only 29% chose to complete it independently over the internet, suggesting that some families may prefer a telephone/in person interview. Similar methodologies could be used to assess barriers and facilitators to DAWBA completion within this population.

Given that a number of families did not complete the full DAWBA after completing the SDQ in these studies, online screening should not be a replacement for clinicians asking about mental health difficulties. Instead, these studies demonstrate that online screening including automatic diagnostic interviews may be a useful and low-cost addition to assessment, particularly in comparison to offering face-to-face psychiatric assessments to all patients.

Additionally, it is possible that use of parent-report only may have under or over-estimated the prevalence of mental health disorders as studies have demonstrated discrepancies between child and parent report of mental health difficulties [37]. However,



studies have also demonstrated that child self-reported SDQ ‘provide little extra information when there is already an adult informant’[38].

Overall, these studies demonstrate that use of an online, automated screening process is a feasible method of detecting mental health disorders in children with chronic illnesses whilst minimising burden on families and clinicians. The process was highly acceptable to families who completed the full screening and could provide a viable option of integrating mental health assessment into routine paediatric care.

## **ACKNOWLEDGEMENTS**

The authors would like to thank Professor Robert Goodman, Professor Bruce Chorpita, Professor Jonathan Smith and all of the neurologists and staff in paediatric neurology clinics at the Whittington Health NHS Trust, North East London Foundation Trust, University College London Hospitals NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust for their support with the studies. This work was funded by the Great Ormond Street Hospital Children’s Charity (Grant Number 17663) and an NIHR Programme Development Grant (RP-PG-0616-10007). The research was supported by the National Institute for Health Research Biomedical Research Centre at Great Ormond Street Hospital for Children NHS Foundation Trust and University College London. Peter Fonagy is in receipt of a National Institute for Health Research (NIHR) Senior Investigator Award (NF-SI-0514-10157), and was in part supported by the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames at Barts Health NHS Trust. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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**What is already known on this topic:**

Common childhood mental health disorders are up to five times more frequent in children with neurological conditions than in those without a chronic illness.

Up to 80% of those with a chronic illness and a mental health disorder are not in contact with child and adolescent mental health services.

Whilst most paediatricians consider it a part of their responsibilities to identify mental health difficulties, there are several barriers to accurate and timely identification.

**What this study adds:**

An online identification process can identify children and young people with chronic neurological conditions who have symptoms of mental health difficulties.

Identification in clinics using the online Strengths and Difficulties Questionnaire with automatic progression to the Development and Wellbeing Assessment minimised burden on families and clinicians.

The process was acceptable to families who completed the full screening and could provide a viable option of integrating mental health assessment into paediatric care.

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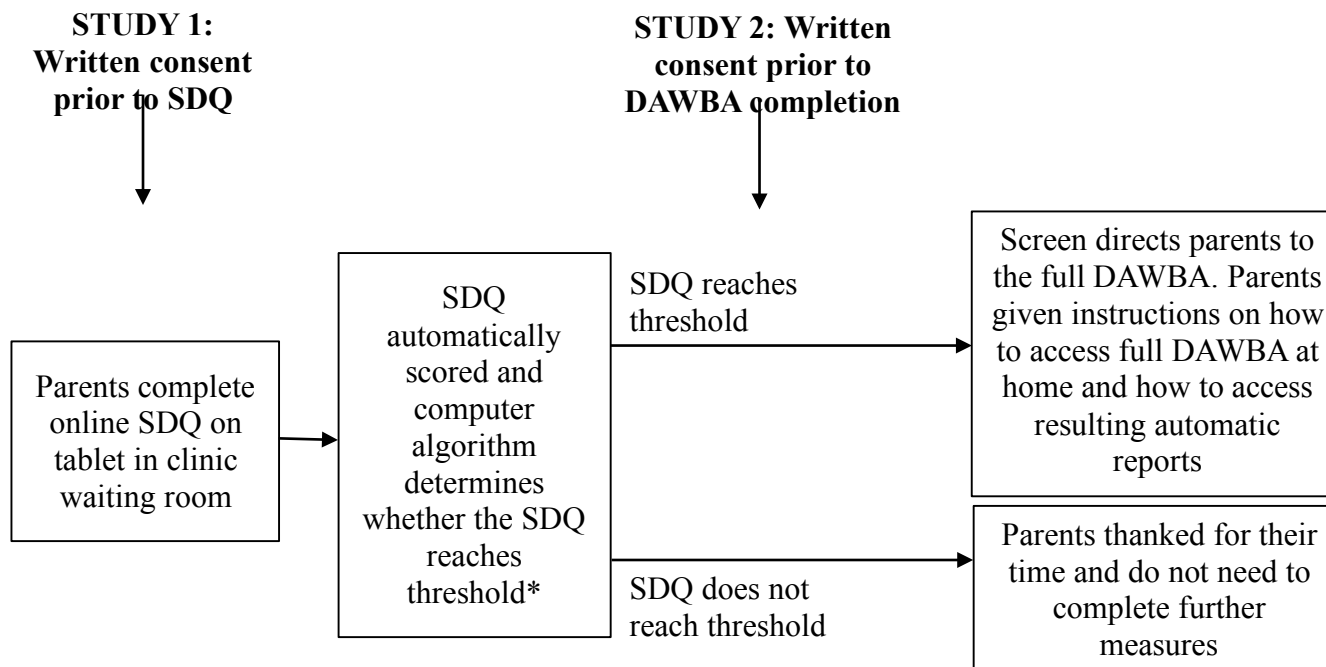
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\*Threshold on the SDQ was defined as the combination of raised symptom score ( $\geq 14$  out of a maximum of 40, which is a score in the 'slightly raised' range or higher) and raised impact score ( $\geq 2$  out of a maximum of 10 indicating a score in the 'high' range or above;[39])

FIGURE 1: The screening process used in both studies

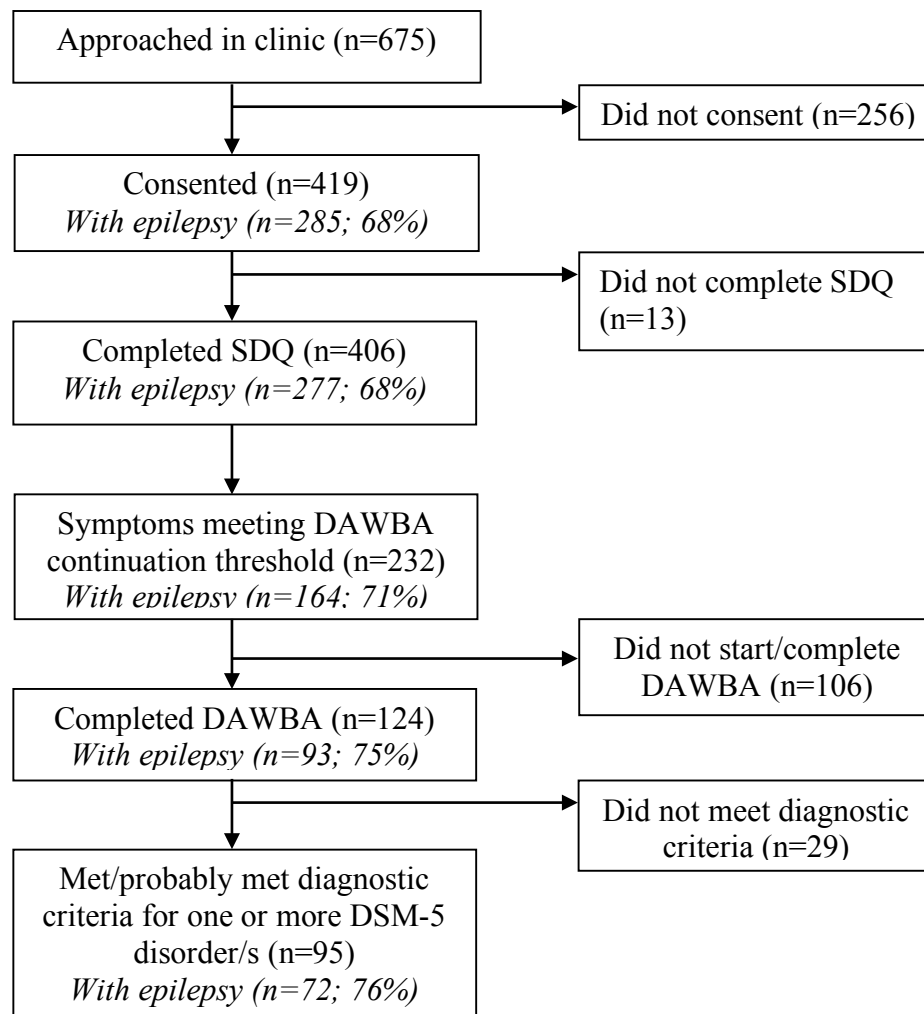


FIGURE 2: Flow chart of study participation for study 1

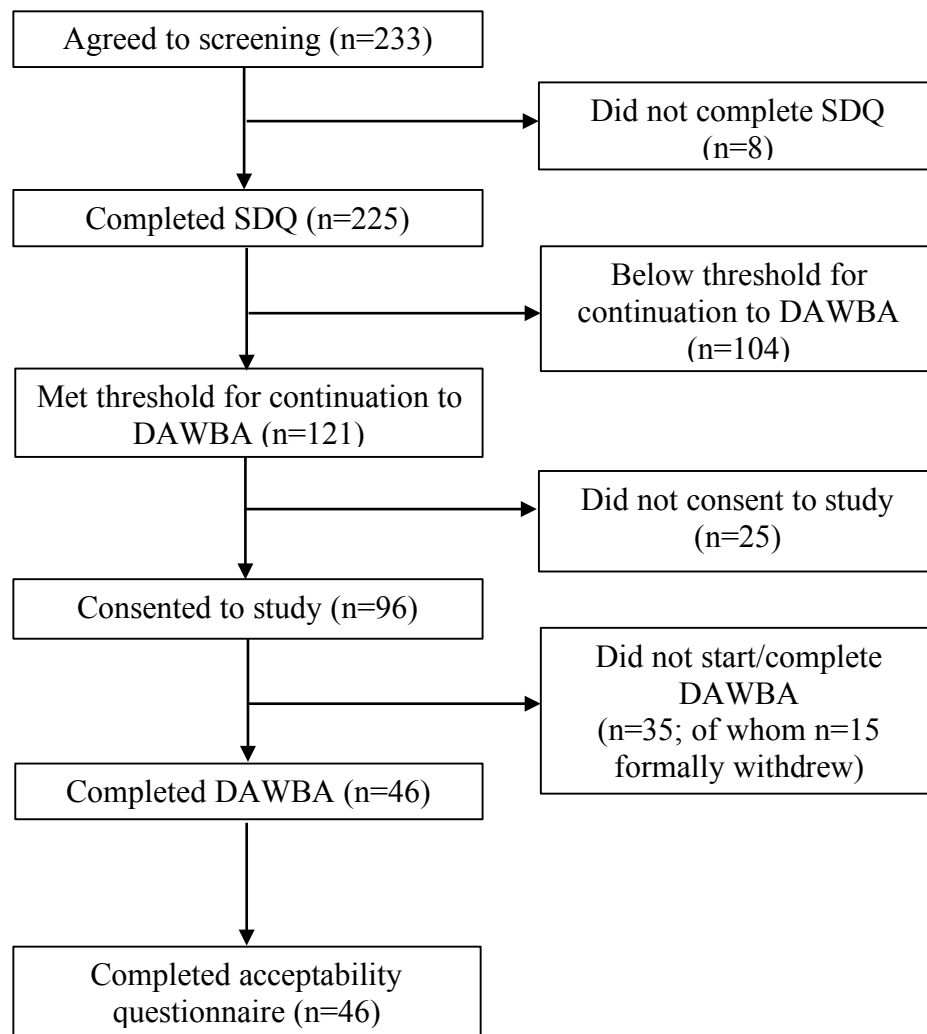


FIGURE 3: Flow chart of study participation for study 2